



DeCrescenzo Family

Ten years ago this month, my husband Joe was diagnosed with hereditary Spinocerebellar Ataxia, SCA2. That marked the day our lives changed and would never again be the same. Since then, our youngest daughter tested positive for SCA2 as well.

We had time to process the diagnosis and vowed not to let it change who we are or alter our daily lives. We found a neurologist who specializes in movement disorders and Ataxia. We also joined two support groups, one at Johns Hopkins Medical Center, and the other with the Chesapeake Chapter NAF. We met so many wonderful, inspiring people who were struggling with Ataxia but always stayed positive, which we admired.

Our next step was to join the National Ataxia Foundation (NAF). We are so thankful we took that step. Our first encounter with NAF was attending the Annual Ataxia Conference (AAC) five years ago in San Antonio, TX. I must admit, it threw me for a loop emotionally and I did spend the first couple days inconsolable at times. I must also admit that the first conference had a huge impact on our lives. It made us realize we are not alone and it gave us strength to move forward. It also allowed us to witness how various age groups deal with Ataxia. So many young people in wheelchairs and with rollators were having the time of their lives, socializing with old friends and making new friends. They were laughing, smiling, and, yes, even dancing at the banquet...it was incredible! Since then, we have become advocates, started our own support group in Delaware, and organized many fundraisers for NAF. We attend the annual Ataxia conferences, where a wealth of information and updates on current research towards a treatment/cure for this rare disorder is available. Also, we volunteer at the conference each year and Joe is now serving on various committees. Research is essential to find a cure; therefore, Joe has participated in numerous research studies over the years.

Our message to the newly diagnosed, and those who feel alone and overwhelmed, is to do everything in your power to stay positive. Some days will be difficult, though if you learn to accept the hand you've been dealt with dignity and to adapt your life style as the Ataxia progresses, it will be easier to get through the more challenging times. Please DO NOT loathe in self-pity nor complain...we are all in the same boat trying to stay afloat, and negativity is exhausting and will NOT change anything. Control your own destiny by continuing your daily life as normal and safely as possible. Join a local support group—get involved! Attend the Annual Ataxia Conference...it is an awesome experience, one you will never forget. Hopefully, what you take away from the conference will help you move forward on your Ataxia journey, knowing you are never alone. NAF has undoubtedly helped us immensely to accept the Ataxia in our family, and with hope in our hearts, we pray a cure will be found in our daughter's lifetime. PLEASE become a member of NAF today!

We have met so many amazing people through NAF who we can truly call our friends, and each year we are excited to welcome new friends to the NAF family. Throughout the year, we keep in touch with our friends between conferences, from across the pond to across the country. We count down the time until we meet again.

Hope to see you at the next NAF AAC!! In the meantime, stay strong.
Cathy & Joe DeCrescenzo